

Users' experiences of BPD services

**Mental health services, care provision, and professional support for people diagnosed with Borderline Personality Disorder: Systematic review of service-user, family, and carer perspectives.**

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## ABSTRACT

**Background:** Mental health professionals' attitudes to people with Borderline Personality Disorder can be negative. No systematic review to date has examined how service-users and their families experience professional care.

**Aims:** To critically synthesise evidence of service-users' and families' subjective experience of mental health care for borderline personality disorder.

**Methods:** Multiple computerised databases were searched using comprehensive terms. All relevant, English language empirical studies were included. We read and critically assessed all papers independently. Study findings were subject to a meta-synthesis.

**Results:** *N=38* studies were included. Analysis revealed four themes for service-users: *assessment and diagnosis; approach of professionals; therapeutic interventions, and service provision*; two broad themes for family / carers: *support, burden, and information*; and *experience of professional and therapeutic approaches*. Both groups expected to receive professional healthcare, and were clear they valued professionalism, respect, compassion and the therapeutic nature of positive relationships with professionals. Expectations were jeopardised where difficulties with knowledge, communication, information sharing, and support were perceived.. **Conclusions** Service-users and families /carers should expect to receive high quality, fair and equal care. In light of current evidence, a cultural shift towards more relational, person centred and recovery-focused care could improve experiences.

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**Keywords:** Borderline Personality Disorder, Emotionally Unstable Personality Disorder, Service-user perspectives, Family /carers perspectives, Service provision, Qualitative research, Systematic review, Meta-synthesis

## INTRODUCTION

Personality disorder (PD) is associated with significant and persistent distress and functional impairments in personal, family, social, educational, occupational and other domains (World Health Organisation [WHO] 2018). Internationally, the prevalence in the general adult population is 5-10% and that of each specific disorder, including borderline personality disorder (BPD) <1% (Samuels, 2011). Despite common misconceptions about its preponderance in women, diagnostic criteria have been met in roughly equal proportions of males and females across studies included in a recent meta-analysis (Mdn 56.1% female , range 49.5 – 63.0%; Vokert et al., 2018). However, the clinical features of BPD can vary considerably between individuals (Coid et al., 2009). UK national treatment guidelines (NICE 2009) encourage diagnosis in adolescence when many features become evident. BPD involves impairment of social, psychological, and occupational functioning (NICE 2009) arising from emotional dysregulation and impaired impulse-control. These core problems are associated with intense fears of abandonment and rejection, instability of self-image, a profound sense of emptiness, angry outbursts and self-mutilating behaviour (Grant et al., 2008; APA, 2013; Mosquera et al., 2014). Approximately 69-80% will self-mutilate or attempt suicide while in a distressed or crisis state of mind, and 10% will complete suicide (Fertuck et al., 2007). The development of BPD is considered to result from interactions between biological/genetic factors, with a 68% heritability rate (Torgerson et al., 2000), and environmental and social factors including childhood experiences with significant others, and potentially sexual abuse (Menon et al., 2016), severe neglect, attachment ruptures, overprotection and invalidating environments (Mosquera et al., 2014).

Despite BPD having a major impact on the lives of those affected directly or indirectly a report in England (NIMHE, 2003) has highlighted the poor treatment and discrimination people with the diagnosis receive. The patient group is considered challenging

by care providers due to problems in interpersonal functioning, creating significant service disengagement and treatment refusal (NCISH, 2018). Relational staff0-service-user difficulties are common and it is known that health professionals sometimes display poor attitudes, knowledge, and skills (Dickens et al., 2016), However there is good evidence for significant recovery and remission from BPD. Ng et al.'s (2016) systematic review found symptomatic remission and improved functioning is possible, with the likelihood of recurrence low. Even better outcomes for individuals could be achieved with early diagnosis and access to recommended treatment (NICE 2009). Dialectical Behaviour Therapy (DBT), and Mentalisation Based Therapy (MBT) are recommended in terms of efficacy and evaluate well (NICE 2009; Paris et al., 2001; Zanarini et al., 2012; Royal College of Psychiatrists, 2018).

Despite significant evidence about the experience of those who use services, it has not to date been systematically identified, appraised, and synthesised. We have therefore conducted a systematic review in order to inform support and education needs, service development, and priorities for future research regarding the experiences of service-users and family carers of mental health services, care, and treatment..

## **METHODS**

### **Design**

Systematic literature review in accordance with the relevant sections of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). Ethical approval was not required.

### **Literature search strategy**

The search was conducted in February 2018 using a population, intervention, comparison, outcome and time-period (PICOT) approach (Riva, Malik, Burnie, Endicott, & Busse, 2012) (see Table 1). Multiple computerised databases (CINAHL, PsycINFO, Medline, Web of Science, ASSIA, Cochrane Library, EMBASE; and for 'grey' literature (ProQuest

[including Dissertations/Theses], OAIster, and WorldCAT) were searched using comprehensive terms (see Table 2). Hand searching of key journals and reference lists of included articles was conducted. All primary research studies that focused on service-users' and/or families' experience or views of mental health care, treatment, support and management for BPD were eligible (see Table 1). Family carers were defined as any adult relative (inclusive of parents, children, or partner) providing any level of informal care or support to the individual. Studies focused solely on professionals' views or the efficacy of care and treatment were excluded. Studies examining views of those diagnosed with any personality disorder, and in which the views of those with BPD specifically were not identified, were excluded.

[Author 1] reviewed titles/abstracts and retrieved the full text version of any paper that described a potentially includable study. [Author 2] reviewed 10% of titles/abstracts to establish reliable study identification; after this, discrepancies were discussed, inclusion criteria clarified, and a further 10% checked by [Author 2]. Inclusion at title/abstract stage was conservative i.e., tending towards over- not under- inclusion. Full text versions of all potentially includable studies were and examined by both authors for a final decision.

Information was extracted using a tool designed for the purpose of this study in order to consistently summarise the information provided in the studies that was relevant for meta-synthesis (see Table 3). Information on study aims, participants' characteristics, received intervention, setting and data collection and analysis methods was extracted. For qualitative studies, first-order (participants' quotes) and second-order (researcher interpretation, statements, assumptions, and ideas) constructs were extracted since this helps to ensure that review findings remain grounded in the original experiences of the participants (Butler et al., 2016).

Studies were quality assessed independently: qualitative studies against a 15 item criteria, adapted from two sources (Critical Appraisal Skills Programme, 2017; Tong et al.,

2007), and mixed-methods studies against a 17-item checklist adapted from the same sources plus items adapted from Greenhalgh (2014). Discrepancies were resolved through discussion and consensus.

## **Analysis**

Analysis employed a process of descriptive meta-synthesis which aimed to triangulate findings from studies encompassing a broad topic area, predicated on a range of epistemological assumptions, and using heterogeneous methods (Finfgeld, 2003; Schreiber et al., 1997). The full text of included studies provides the data corpus; analysis involves identification of reciprocal and refutational relationships rather than an interpretative deconstruction of the underlying meaning of data (Finfgeld, 2003). Papers were read and analysed independently. Then, in collaboration, initial coding of first- and second-order constructs in qualitative studies was conducted and units with similar codes sorted into thematic headings and subheadings. Analyses were then discussed, summaries written and rewritten, and checked before final synthesis. Quantitative results were then included in the analysis; where possible under existing themes but where this was not possible amendments were made. Studies were included in analyses irrespective of their quality; however, more robust studies were assigned greater weight in integration.

## **RESULTS**

The search strategy yielded N=38 studies (see Figure 1) published between 1999 and 2017, conducted in nine countries (UK, k=18; US k=7; Australia k=4; Sweden k=2, Netherlands k=2, New Zealand k=2; Canada k=1, Ireland k=1, Norway k=1). Most (k= 34, 89%) focused on service-users' experiences while k= 5, (13%) involved families and/or carers. Studies were conducted within inpatient services k= 6 (15%); community mental health services, k=16, (40%), both or other, k=18, (45%). Study quality was generally rated highly; all qualitative studies achieved more than half of quality checks (Mdn=13, 5, range=10-16), and all but one of the mixed methods studies met almost all quality checks

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(Mdn=16, range 8- 16). Six (15.0%) papers had explicit evidence of study co-production with service-user experts-by-experience.

### **Service-user experience**

Meta-synthesis resulted in four higher order themes: assessment and diagnosis; professionals' approach; therapeutic interventions; and service provision. All four themes emerged from service-users' accounts of their interactions with health professionals and services. Analysis of studies of experiences of family carers resulted in two broadly similar themes: support, burden, and information; experience of professional and therapeutic approaches.

*Assessment and diagnosis.* Participants reported receiving very little information about professionals' roles, the purpose of their contact during assessments, or about the BPD-diagnosis once confirmed. They perceived reluctance to share their diagnosis with them and, once broached, reported it was conducted insensitively with little opportunity for discussion, exploration, or education (Fallon, 2003; Morris et al., 2014). Participants felt unsupported, confused about what to expect, and pessimistic about their prognosis (Bilderbeck et al., 2014). One study highlighted service-users' desire for a quicker diagnostic process (Rogers & Acton, 2012), though in others the BPD-diagnosis was itself questioned, being seen as unhelpful, stigmatising, arbitrary (Morris et al., 2014), interfering with development of self-identification, and symbolic of rejection by services (Bradbury, 2016; Bilderbeck et al., 2014; Horn et al., 2009; Rogers & Dunne, 2011; Wolfendale-Smith, 2016). Some believed that diagnosis triggered prejudice in staff including dismissal of psychotic-type symptoms as 'malingering' (Rogers & Acton, 2012). For others, diagnosis conferred hope via the possibility of effective treatment (Rogers & Acton, 2012), provided validation, alleviated self-blame for previous harmful behaviours (Bilderbeck et al., 2014), and provided clarity and a sense of control (Horn et al., 2009).

**Professionals' approach.** Service-users placed prime importance on feeling 'treated like a person' (Nehls, 2001: 7) and valued the potential of individual practitioners to make a difference in their lives (Veysey, 2014). Trust was seen as key to establishing and maintaining relationships with a care co-ordinator (Bradbury, 2016); over time, participants felt increasingly able to share aspects of themselves. A Delphi study conducted in a specialist service found respect, professionalism, support and practicalities central to service-user's needs. Participants identified psychiatric professionals as facilitative of opportunities for service-users to support one another (Webb & McMurrin, 2009). Individuals commonly sought professionals who they perceived as accommodating and willing to engage, and considered them to have the potential to raise their self-esteem and hope (Bilderbeck et al., 2014; Veysey, 2014). Respect, calmness, patience, knowledge, flexibility, and empathy (Borschman et al., 2014; Bradbury, 2016; Cunningham et al., 2004; McSherry et al., 2012; Perseus et al., 2003; Webb & McMurrin, 2009) were all desirable attributes. Preferred qualities included boundary-setting, and containment of self-harm ideation and distress (Bilderbeck et al., 2014; Bradbury, 2016; Fallon, 2003). Professionals demonstrating understanding of emotions and behaviour through detailed formulations reduced feelings of criticism and blame (Morris et al., 2014). Further, those who discussed current problems and goals of admission at the commencement of a preventative inpatient stay were thought to alleviate suffering and enhance a sense of control over treatment (Koekkoek et al., 2009). Similarly, talking with a nurse at the start of a brief crisis admission helped service-users to overcome doubts about help-seeking and facilitated goal-based care-planning (Rogers & Dunne, 2011). Connecting with others, receiving emotional and practical support during periods of crisis, and having a case manager were highly valued (Borschman et al., 2014). The pre-planned longevity of case management was perceived to safeguard the establishment of a long-term relationship, a sometimes novel experience. Service-users readily attributed an

enhanced sense of self-sufficiency and reduced need for crisis care to their relationship with their case manager (Nehls, 2001).

Evidence of negative and judgemental attitudes from professionals in psychiatric wards and Emergency Departments, however, was also preponderant. Webb and McMurrin (2009) reported that General Hospital staff treating service-users following self-harm and suicide attempts responded to them poorly and did not meet their needs. Similarly, Fallon (2003) found Emergency Department care to be perceived as limited to wound dressing and medication; emotional support was felt to be both implicitly and explicitly out of scope (Fallon, 2003). Perceived discrimination negatively affected service-users' experience (Veysey, 2014; Wolfendale-Smith, 2016; Webb & McMurrin, 2009); these experiences seemed to link to a greater sense of treatment-futility and pessimism about ever being able to manage their mental health (Dor, 2015). Bradbury (2016) highlighted the issue of the suitability of individual practitioners based on their characteristics and qualities; one female participant was concerned about being allocated a male care co-ordinator, and another that her care co-ordinator's approach left her feeling annoyed. Similarly, in three studies (Borschman et al., 2014, Hegge, 2011; Perseus, 2006) service-users recalled unhelpful interactions with professionals during crisis; commonly used adjectives included: 'judgemental', 'dishonest', 'dismissive', 'disrespectful', 'patronising', and 'sarcastic'. These terms reportedly added to suffering, and perceived disrespect or condemnation were viewed as, at best, indifferent or even hostile. Service-users believed they were viewed as difficult, challenging, complex, high risk, and sensed a reluctance to provide care (Morris et al., 2014). They considered this to be related to professionals' limited knowledge and understanding of their difficulties and self-harm related needs. As a result, they struggled with openness and honesty, and experienced a fear of professional abandonment and rejection (Bradbury, 2016; Morris et al., 2014; Rogers & Dunne, 2011, Webb & McMurrin, 2009). Likewise, service-users in a therapeutic community study considered that professionals applied rules punitively,

and demonstrated little understanding of the reasons behind their fears and behaviour (Chiesa et al., 2000). More generally, professionals' poor knowledge and skills were perceived to contribute to their negative attitudes, dismissiveness, lack of sympathy, and insensitivity (Rogers & Dunne, 2011). This kind of behaviour from professionals was felt to activate negative thoughts, acts of self-harm, or suicide attempts (Hegge, 2011). Likewise, feeling misunderstood reportedly led to intense feelings of hopelessness, and to questioning of the purpose of the relationship (Bradbury, 2016).

A survey found two thirds of respondents with a BPD-diagnosis reported being treated disrespectfully by health professionals. While half said their General Practitioner (GP) was supportive, this professional group were rated the least helpful overall: one quarter said their GP avoided addressing their BPD-diagnosis or lacked confidence in treatment. Health professionals were reported to have failed to help respondents manage their feelings (McMahon & Lawn, 2015b). Similarly, service-users reported GPs were negative, lacked time for them, and misunderstood their level of crisis (Webb & McMurrin, 2009). This was echoed in brief crisis admissions where service-users reported that, when professionals offered little contact, they had feelings of increased tension, abandonment, loss, and anger leading to a negative perception of care and more maladaptive coping behaviours (Helleman et al., 2013). Care co-ordination was believed to be prioritised by professionals over therapeutic relationship building, while psychological and emotional support was viewed as inadequate, particularly during crisis (Morris et al., 2014; Nehls, 1999; Veysey, 2014). Bradbury (2016) identified that, despite the care co-ordinator's role not being viewed as overtly therapeutic, it had the potential to contribute beneficially *or* counter-therapeutically towards practical and emotional support.

***Therapeutic interventions.*** Service-users felt that information about therapeutic interventions was scarce (Fallon, 2003; Nehls, 1999; Morris et al., 2014). Nevertheless, studies examined users' experiences of Dialectical Behaviour Therapy (DBT;  $k=6$  studies),

Schema Therapy (ST;  $k=1$  study), and art combined with Cognitive Behavioural Therapy (CBT;  $k=1$  study). Provided over a 1-2 year period, these therapies were favourably viewed when individuals felt they had developed regulation skills including tolerance-skills related to distress, and were socialising more (Cunningham et al., 2004; May, 2015; Perseus et al., 2003; Perseus, 2006). Additionally, they reported improved assertiveness, optimism, realistic expectations (Hummelen et al., 2007; McSherry et al., 2012), and felt they were building supportive, less abusive relationships (Cunningham et al., 2004; Hodgetts et al., 2007; May, 2015; Perseus et al., 2003; Perseus, 2006).

Significant DBT-programme experiences included perceived acceptance, respect (McSherry et al., 2012, Perseus, 2006), equality and non-judgementalism (Cunningham et al., 2004; Hodgetts et al., 2007) depending on the therapist's skills (Cunningham et al., 2004; Perseus, 2006). Therapeutic relationships were sometimes viewed as friendships or partnerships (Cunningham et al., 2004) with service-users considering that therapists validated their experiences while offering encouragement (McSherry et al., 2012). Some felt ongoing personal development continued post-therapy, and reported extinction of suicidal thoughts and greater enjoyment in life (McSherry et al., 2012; Perseus, 2006). DBT was described in some studies as life changing or lifesaving (Cunningham et al., 2004; Perseus et al., 2003). More specifically, it was identified as an active agent (Hodgetts et al., 2007) which, through learning and application, brought structure, and new skills that aided emotional regulation and distress-tolerance (Cunningham et al., 2004; Hodgetts et al., 2007). DBT group therapy was perceived to provide mindfulness skills which assisted with conquering self-destructive impulsivity (Hodgetts et al., 2007; Perseus et al., 2003) and was experienced as supporting identity-formation. Service-users valued the opportunity to meet others with similar experiences and reported a sense of belonging (Hodgetts et al., 2007; McSherry et al., 2012; Perseus, 2006), reduced loneliness and stigmatisation, and greater social confidence (McSherry et al., 2012). Some wanted therapeutic groups to have greater

longevity and believed this would result in improved skills (Cunningham et al., 2004). Others felt groups were rushed, or found them a difficult setting in which to express themselves (McSherry et al., 2012). Hodgetts et al. (2007) identified that for some DBT focussed overly on self-harm while overlooking eating problems and past trauma; led to a reported dissonance between aspirations to overcome personal issues and the general focus of treatment. Barnicot et al's (2015) investigation of barriers to effective DBT skills training for service-users reported that state anxiety and limited theoretical grasp of the material led to participants feeling emotionally overwhelmed and unable or unwilling to use the skills.

In group Schema Therapy, service-users experienced greater self-understanding and found the approach enabled better awareness and connection with their emotional processes (May, 2015). Participants identified this as emotionally confrontational yet necessary, and they considered the group facilitated a sense of connection among members. However, this seemed to depend on the therapist's ability to manage group conflict. Elsewhere, service-users who withdrew from an outpatient art and psychotherapy group felt they would fare better in a one-to-one with the therapist as they felt vulnerable in the group; others reported transitioning from an inpatient group had been too distressing, while some stated they were no longer interested and wished to escape services (Hummelen et al., 2007).

Common elements of psychological therapy associated with improved recovery included structure, goal orientation, flexibility, healthy relationships, and support network expansion (Katasakou, 2016; Lariverie, et al., 2015). One study identified therapy that enabled self-exploration and problem solving as helpful but, where the focus was solely on understanding the past, therapy was unhelpful. Further, service-users perceived regular, intensive therapy, a supportive therapist, and a managed-ending as key factors (Katasakou, 2016). However, many considered the term 'recovery' to be an inappropriate and ultimately impossible therapy-outcome, requiring in effect a new personality (Katsakou et al., 2012), or

potentially leading to complacency and failure to self-monitor for relapse (Lariverie et al., 2015).

In a study exploring views of pharmacological therapies, involvement in medication decisions and receiving information or support to manage side effects were believed to be essential. Some considered medication unnecessary or its value over-emphasised at the expense of psychological therapies (Rogers & Acton, 2012). In contrast, a study of women from an inpatient secure unit prescribed clozapine for BPD, identified a good relationship with their prescribing physician as important. They associated clozapine treatment with profoundly positive behavioural, cognitive, affective, and social benefits including reduction in impulsivity, aggression, self-harm and improved relationships. For some, clozapine was the primary method of managing their BPD and others found it facilitated their participation in psychological therapy (Dickens et al., 2016).

***Service provision.*** Experiences were investigated across inpatient and community settings. Several studies reported that service-users felt information about service availability and provision was poorly explained (Bradbury, 2016; Fallon, 2003; Morris et al., 2014; Nehls, 1999). In one study a participant described how her care co-ordinator had left employment without telling her leaving her confused and upset (Bradbury, 2016). More encouragingly, adult mental health services were viewed as professional, providing useful therapy, and enabling peer-to-peer support, with areas identified for improvement being access, and relational and compassion aspects (Morris et al., 2014). Studies emphasised that, when it did happen, gaining access to effective treatment provided a community and reduced stigma (Horn et al., 2009; Wolfendale-Smith, 2016; Webb & McMurrin, 2009).

Eight studies investigated inpatient care including, a therapeutic community, mainstream, specialist, and forensic settings. A therapeutic community was reported as anti-therapeutic, inflexible, and institutionalised, which led to service-users citing these as reasons for treatment-withdrawal. Difficulties were found with a perceived sense of responsibility for

supporting their peers, and a subculture of inter-user bullying and intimidation (Chiesa et al., 2000). Individuals detained in a forensic inpatient unit highlighted limited choices and control which they experienced as disempowering and ultimately responsible for their expressing suicidal intent as a means of gaining personal control (Lovell & Hardy, 2014; Wilkinson, 2008). Specialist inpatient services, were considered to have a greater emphasis on promoting psychological therapies than mainstream services (Morris et al., 2014). In mainstream care, pre-emptive, crisis-preventative hospital admission was reported to help users to contain emotions, and prevent self-harm and suicide attempts (Fallon, 2003; Helleman et al., 2013), some were ambivalent about behavioural containment and expressed anger at the limits placed on their autonomy (Fallon, 2003). Regular, planned admissions were viewed as facilitative of a break from daily responsibilities, promoting rest and recovery, and contributing to crisis prevention (Koekkoek et al., 2009). One study emphasised users' reported need for gender-specific wards, dissatisfaction with discharge planning and post-discharge support (Rogers & Dunne, 2013).

Two studies examined experiences of community-based approaches involving individually-assigned case managers (Nehls, 2001; Bradbury, 2016). These roles involved practitioners' maintaining helpful, practical relationships with service-users; reported benefits included supportive and understanding relationships with their case manager / care co-ordinator which were influential in promoting community-living through education, coaching, emotional and practical support. They were viewed by service-users as more helpful than contact with psychiatrists (Nehls, 2001; Bradbury, 2016). Further, Bradbury's (2016) study identified that care coordinator relationships, when successfully performed, facilitated therapeutically beneficial secure attachments. In this study, service-users, identified responsibility for establishing boundaries and maintaining professionalism as lying squarely with the care co-ordinator, but they understood trust as a two-way process. Accordingly, a specialist service offering mixed therapeutic approaches was positively

appraised as professional and therapeutic (Webb & McMurrin, 2009). In contrast, the Care Programme Approach (CPA), a UK designed programme to provide a structured process for individuals receiving multi-disciplinary care, was reportedly poor in terms of involvement and meeting informational needs, leading to dissatisfaction and disempowerment with the planning (Hegge, 2011; Rogers & Dunne, 2013).

Finally, an out-of-hours service was valued and used frequently; service-users felt service responses had improved over time, yet some remained inaccessible and unhelpful (Fallon, 2003).

### **Family and carers**

Five studies, four qualitative, focused on family and carer's experiences. The small number of studies necessarily means that, compared with evidence about service-users themselves, the analysis of results and generalisability of conclusions from these studies is limited. However, two broad themes can be considered: support, burden, and information; and experience of professional and therapeutic approaches.

*Support, burden and information.* Giffin (2008) reported that participants' criticised treatment planning because it focused only on the identified 'patient' rather than taking account of mother-daughter, clinician-patient, and hospital-patient relationship dyads. Parents had concerns about housing opportunities to promote independent living. They requested recognition of the burden that their child's condition placed on them emotionally and financially. Reflecting the different funding models for care across studies, many carer and family comments addressed treatment funding issues rather than the content of that treatment per se (Buteau et al., 2008, 2013; Dunne & Rogers, 2013; Giffin, 2008; Lawn & McMahon, 2015a).

The reported merit of support groups was mixed but highlighted that carers most valued one-to-one contact and BPD-specific information and support. Some found it difficult to be open about their family member's diagnosis and difficulties in a mixed support group

(Lawn & McMahon, 2015a). Access to online and face-to-face support programs (Buteau et al., 2008; Dunne et al., 2013; Giffin, 2008) were viewed positively. Likewise, one study found that families experienced supportive respite through a range of services such as, day programmes, psychosocial group activities, community-based support, and residential programs (Dunne & Rogers, 2013).

In three studies, participants perceived they received inadequate information at the time of their relative's diagnosis and an absence of assistance from professionals when trying to obtain information and support (Buteau et al., 2008; Giffin, 2008; Lawn & McMahon, 2015a). One identified families' claims of numerous misdiagnoses, exclusion from the treatment process, miscommunication, and fragmented care between services, professionals and themselves (Giffin, 2008). In a survey, two thirds of respondents reported that medical professionals did not explain what BPD means, one in twenty did not understand it even when explained, and only one third received a full explanation of the diagnosis and understood it. Similarly, more than half reported that health professionals had not helped them understand BPD and many reported not being taken seriously. In one study, families sought explanations about the connection between BPD and their genetic, mental health, and family histories. Information and support to help understand the condition had alleviated guilt and self-blame (Buteau et al., 2008). Four studies reported families / carers sought better communication, information, and advice on how to manage emotional and behavioural difficulties, situations, crisis and conflicts that arose with their relative (Buteau et al., 2008; Dunne & Rogers, 2013; Giffin, 2008; Lawn & McMahon, 2015a).

***Experience of professional and therapeutic approaches.*** A perceived lack of sensitivity from professionals regarding families' concerns and needs (Giffin, 2008; Buteau et al., 2008; Dunne & Rogers, 2013) was evident. For example, carers felt professionals were unsupportive in meetings which were experienced as frustrating and intimidating. Some experienced difficulty asking questions when their relative was present and considered they

were inappropriately relied upon when making treatment decisions (Giffin, 2008). Similarly, there was censure for the UK Care Programme Approach (CPA) because family and carers had not seen or been consulted about a care plan; and associated CPA meetings were reportedly unprofessional, with poor staff attitudes perceived, failure to listen to the carers' perspective and an experienced 'tick-box' process (Dunne & Rogers, 2013). In one study, family members perceived an insinuation they were to blame for their child's BPD (Giffin, 2008); in another, comments such as 'it's just behaviour' were perceived as unhelpful and stigmatising with family and carers believing many professionals had little understanding of their caring role, or of BPD itself (Dunne & Rogers, 2013). There were mixed feelings about the helpfulness of telephone helplines. Some were responsive and enabled them to talk over any problems while others perceived complete disinterest (Dunne & Rogers, 2013); others described staff as willing to engage and listen to them, easing demands of life as a carer, but some felt viewed as overly anxious, and did not feel heard; some spoke about feeling traumatic stress compounded by stigma and guilt (Buteau et al., 2008).

A survey revealed that many clinical services and professionals, including psychiatrists and relationship counsellors, went un-accessed. Some participants rated psychiatrists and psychologists as most helpful, and reported General Practitioners to be a good source of support, but education and training were felt necessary to shift negative attitudes, discrimination, and improve recognition of carer needs (Lawn & McMahon, 2015a). Families reported a dearth of trained therapists or access to psychotherapy (Giffin, 2008). Some families criticised the lack of a written treatment plan for hospital admissions even when extending several weeks, perceiving therapeutic interventions as ad hoc with inexplicable between-patient treatment variation, and discharge plans reportedly made without consultation (Buteau et al., 2008). Additionally, 73% of carers surveyed had not received a crisis plan and almost half had not been involved in decisions about care.

## **DISCUSSION**

This review has provided a critical synthesis of evidence on families or carers experiences of professional mental health care for BPD. Half the included studies were published in the last five years suggesting greater recognition of the importance of user and family experience. There is considerable evidence that service-users, their families and carers have firm expectations about the professional support they or their relatives should receive including professionalism, respect, compassion, clinical knowledge, effective interventions, and positive non- stigmatising attitudes. On many occasions these basic expectations were perceived as inadequately met, lacking their involvement, or consideration of their needs or rights. They were clear where provision made a difference, placing value on the therapeutic nature of positive relationships with professionals; considered essential in best practice guidance (NICE, 2015). However, our review revealed this was jeopardised by significant perceived difficulties in attitudes, therapeutic approach, skills and knowledge of clinical professionals leading to a failure to establish therapeutic relationships and hampering recovery. They expected a caring and sensitive manner from professionals and a recognition of their needs, yet they commonly expressed a directly contradictory and discriminatory experience (Bilderbeck et al., 2014; Buteau et al., 2008; Morris et al., 2014; Lawn & Mc Mahon, 2015a; Lawn & Mc Mahon, 2015b;). Where care was perceived as poorly organised and professionals' attitudes dismissive (e.g. Chiesa et al., 2000; Rogers & Acton, 2012), this created barriers to development of therapeutic relationships, potentially leading to pejorative and discriminatory clinical practices (Jeung and Herpetz 2014). While the available literature suggests that many of these concerns were mirrored in the families or carers of people with a BPD-diagnosis the simple weight of evidence is less.

Problematic relationships are a recognised feature of BPD due to emotional instability, fear of abandonment, and distrust (Grant et al., 2008); further, individuals' sensitivity to professionals may be exacerbated by the rejection and emotional neglect commonly experienced in childhood (Staebler et al., 2011). Professionals need to be mindful

of this when building therapeutic relationships (McMain et al., 2015). Gunderson (2014) considers that it is the very nature of BPD which may reinforce the difficulties experienced in the development of therapeutic relationships, particularly due to emotion dysregulation, impulsivity, and interpersonal difficulties that individuals with a BPD diagnosis experience. This can lead to interactions producing intense reactions from professionals and leading to difficulties with trust, and relationships which are difficult to maintain. This was evident in a study in which therapeutic community treatment was poorly evaluated (Cheisa et al., 2000); or where dismissive, disrespectful and counter therapeutic interactions experienced (Borschman et al., 2014; Hegge, 2011; Perseius, 2006). According to Bender (2005) strategies which support positive relationships include: nurturing emotional awareness; structuring treatment; responsiveness; supervision or team involvement; and exploring ruptures. This may explain why specialist services (e.g. Webb & McMurrin, 2009), and intensive interventions such as case management (Bradbury, 2016, Nehls, 1999) were favourably viewed as providing positive relationships, reliable care and support across the longer term. Similarly, time limited and structured planned hospital admissions to prevent crisis reflected evidence based guidance (NICE, 2009) were experienced by service-users as helping them receive necessary support and temporary asylum to control their condition (Koekkoek et al., 2009).

Equally, we found that psychological therapies where individuals received regular intensive therapy and professionals followed evidence based programmes were perceived as therapeutic and supportive (e.g. Bradbury, 2016; Cunningham et al., 2004; Hodgetts et al., 2007; McSherry et al., 2012; May, 2015; Perseius et al., 2003; Perseius, 2006); and central to recovery (e.g. Katsakou et al., 2012; Lariverie et al., 2015). Here, nurturing the development of emotional awareness within individuals is a key aspect of psychological therapies; professionals are advised to adopt an open, inquiring, and neutral set of attitudes to support this, and to minimise intense reactions between themselves that may be counter therapeutic

(McMain et al., 2015). Bender (2005) argues that therapeutic relationships with BPD-diagnosed individuals require reflective practice and the therapeutic use of self, with characteristics including: self-awareness, self-knowledge, and empathy, attention to ethics, boundaries, and limits within the professional role. Positive communication techniques including active listening, silence, open-ended questions, restating, reflecting, clarifying, validating, focusing, summarizing, and being mindful of one's own values and the differences between professional and service user are central to practice. A recent study (Bowen, 2013) into clinicians' accounts of good practice within a specialist service reported these elements as vital, alongside working with structured therapeutic frameworks including: MBT, DBT, a recovery focus to care, and access to supportive supervision. Here nurses' attitudes, knowledge and skills were evidently more positive and perceived as effective with significant optimism for service users' recovery and could be adopted by professionals in mainstream services.

Several accounts of poor experiences and difficulty accessing care and treatment suggest an absence of practitioners educated in psychological therapies, or with necessary therapeutic skills and professional attitudes (Bradbury, 2016; Dunne & Rogers, 2013; Nehls, 2001). Additionally, inadequate services or structures were reported (Buteau et al., 2008; Fallon, 2003; Giffin, 2008; Lawn & McMahon, 2015a; Lawn & McMahon, 2015b; Nehls, 1999; Rogers & Acton, 2012; Rogers & Dunne, 2011, Webb & McMurrin, 2009) raising implications for services to develop improvement strategies. McMain et al., (2015) suggest a more inclusive and therapeutic approach to care, with practitioners being taught a range of knowledge and skills to support individuals experiencing a PD rather than depending upon highly specialized DBT therapists and specialist services. Greater accessibility could be promoted by adopting recommended approaches such as 'General Psychiatric Management' based on a case management model, and 'Structured Clinical Management' utilising principles from MBT (Bateman & Fonagy, 2010). Both have been identified as effective as

DBT, showing substantial improvements across an array of clinical outcomes including stability and drop out (Choi-Kain et al., 2017).

Family and carer participants reported a perceived absence of understanding about their role and support for the challenges they face. They understood this to create barriers to receiving support for both themselves and their relatives particularly during times of crisis. They also perceived a lack of sensitivity towards their needs and concerns, and believed they were viewed as over anxious. They expressed financial burden caused by being unable to work due to the caring role, or having to pay for treatment. Furthermore, navigating the mental health system was found to be complicated and difficult as was accessing information about BPD and locating treatment. There was appreciation for psychotherapy, community groups for relatives, and respite care. A systematic review (Bailey and Grenyer, 2013) examining the burden and support needs for carers of people with personality disorder found objective (financial difficulties, household disruption) and subjective (embarrassment, guilt, stigma) problems of greater magnitude than in a similar study of carers of people with mood, substance use, and psychotic disorders (Page et al., 2006). Additionally, a sense of grief was found to be significantly greater than for other serious mental illness including schizophrenia and major affective disorders (Stuering et al., 1995). The review reported carers to experience poor mental health including depression and anxiety; and suggested that supportive group interventions can reduce burden and grief and benefit their health (Hoffman, 2005; Hoffman, 2007). Other suggested interventions for carers include: psycho-education, support groups, supportive education, intensive behavioural family therapy, and problem solving (Chien et al., 2005; Elliot & Brown, 2011) but these have yet to be trialled for carers of BPD-diagnosed individuals.

There is a need to improve the approach of professionals. The attitudinal deficit must be addressed by creating opportunities for training and education; however, it is not clear what works best (Dickens et al., 2015). Lessons can be learned from service users and families who viewed their care as positive and attained a degree of recovery. Those receiving

psychological therapies noted better relationships with their therapists, and credited the resultant therapy with assisting in developing skills and emotion regulation, and subsequently reducing suicide and self-harm. Therefore, in accordance with practice guidance, all service-users with a diagnosis of BPD should be offered a course of psychological therapy (APA, 2013; ICD 11, 2018; NH&MRC, 2012; NICE, 2009). Additionally, services should have an identified care pathway particularly for periods of crisis.

### **Limitations**

Our review is limited by the absence of non-English language studies and may not be generalizable beyond associated countries. We also chose not to include the experiences of individuals and carers in the wider category of personality disorders. Few studies focused on family carers' experience and there is significant scope for further research. It is necessary to involve family carers in a study into their support needs and to ensure that any resultant intervention framework is guided by them. Further research into training and education for professionals, specifically whether this improves the experience and perceived quality of care that BPD-diagnosed individuals receive, is required. Only a small proportion of studies included in this review had clear evidence of co-production with service-users or family carers and this should be remedied in future research.

### **Conclusions**

Service-users and families should expect to receive high quality, fair and equal care from professionals and services. In light of current evidence and the findings of this review a cultural shift towards more relational, person centred and recovery focused care could improve service-user and family carer experiences. This review identifies professional care and treatment as a perceived step towards this and future care provision should focus on enablement of individuals to achieve these important goals.

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**Table 1: Inclusion and exclusion criteria**

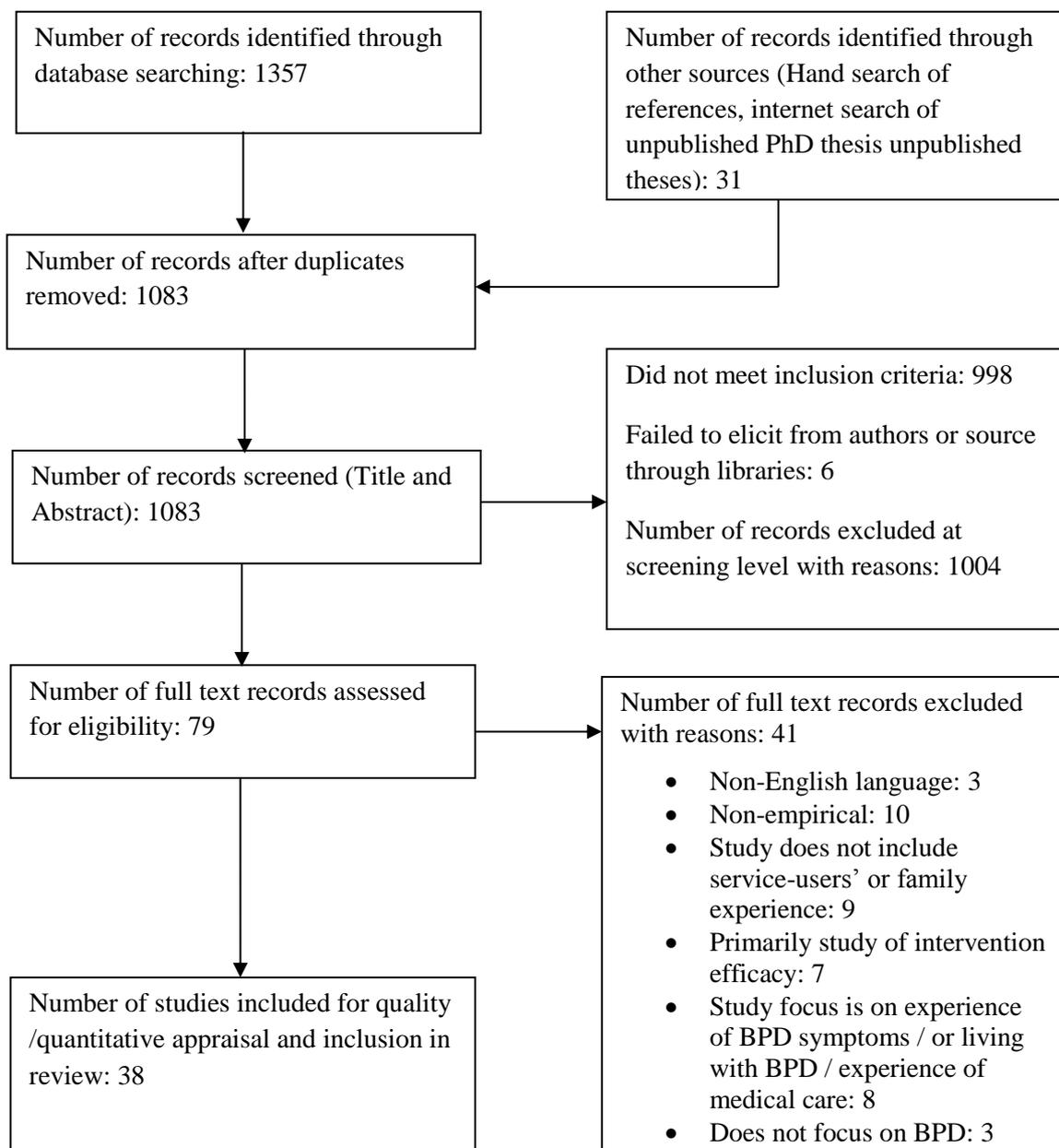
<b>Parameter</b>	<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
<b>Population</b>	Sample includes service-users, families, carers	Samples solely comprising professionals or people who do not have a diagnosis of or a family member with a BPD diagnosis
<b>Intervention/Focus</b>	Experience of, views, perspectives of care, treatment and management of borderline personality disorder	Care and treatment related to personality disorder in general with no separate data for borderline personality disorder.  Specific care and treatment for substance misuse, depression, schizophrenia, bipolar, suicidality, obsessive compulsive disorder, sexual abuse.
<b>Comparator</b>	Healthy population, other disorder, no comparator.	None
<b>Outcomes</b>	Qualitative or quantitative accounts, descriptions, comparisons.	Opinion, reviews
<b>Time period</b>	Any up to February 2018	None

Users' experiences of BPD services

**Table 2: Example search: CINAHL**

	<b>Search terms (Title, Abstract, Keywords)</b>	<b>Results</b>
1)	Borderline personality disorder OR Emotionally unstable personality disorder	13,895
2)	Service-user* OR patient* OR people* OR individual* OR client* OR consumer*	8,968,067
3)	Famil* OR carer* OR parent*	1,929,804
4)	S2 OR S3	10,213,495
5)	S1 AND S4	10,340
6)	View* OR experience* OR perception* OR participation* OR involvement* OR sense* OR contact* OR encounter* OR perspective* OR impression* OR opinion* OR judg*	4,495,595
7)	AB care* OR AB treatment* OR AB intervention* OR AB nursing* OR AB assistance* OR AB approach* OR AB management*	7,892,058
8)	S5 AND S6	3,215
9)	S7 AND S8	1,820
10)	English language only	1,355

*Figure 1: Flow diagram of literature search modified from the PRISMA flow diagram (Moher et al. 2009)*



## Users' experiences of BPD services

**Table 3: Details of included studies**

Author / country / date	Aim / research questions	Participants and setting	Method/ Data collection	Findings
Barnicot et al. (2015) UK	a) What are clients experiences of barriers to dialectical behaviour therapy skills training and how were they overcome? b) Compare experiences between treatment completers/non-completers.	40 service-users with BPD-diagnosis	Qualitative. Critical realist approach, semi structured interviews, thematic analysis	<b>Barriers:</b> Anxiety during skills groups, difficulty understanding the material. Overwhelming emotions. <b>Overcoming barriers:</b> Training by peers, group and individual therapists, friends and family. Treatment completers described less anxiety during the skills groups and more likely to report overcoming barriers.
Bilderbeck et al. (2014) UK	To investigate the experiences of assessment and diagnosis among patients with mood instability	28 Service-users (4 BPD-diagnosed, 7 no diagnosis)	Qualitative semi-structured interviews. Thematic analysis	<b>Needs:</b> Explanation and help, consistent continuous care, to feel involved and informed, and to be acknowledged; but they often felt dismissed, discredited; and struggled to communicate.
Borschman, et al. (2014) US	To investigate crisis-treatment preferences	41 service-users with BPD-diagnosis	Qualitative semi-structured interviews. Thematic analysis	Participants had previously experienced unhelpful interactions with professionals and wanted to avoid a repeat. Described clinicians as: “judgmental,” “dishonest,” “dismissive,” “condescending,” “disrespectful,” “sarcastic,” “misleading,” “impatient,” “patronizing,” “indiscreet”, “not taking seriously” and “treating me like a child.” Said they had “not followed through on promises”.
Bradbury (2016) UK	To explore the relationship between those with a BPD-diagnosis and their care coordinators	8 service-users with BPD diagnosis	Qualitative Semi structured interviews	Themes: 1. Trust 2. Qualities of the care coordinator; 3. The complexity of the relationship; and 4. Developing a safe base.
Buteau et al. (2008) US	To learn directly from family members their experiences of care for their relative	12 Families of people diagnosed with BPD	Qualitative, semi-structured interviews Delphi study, thematic analysis	Difficulty accessing information about BPD; navigating the mental health system; locating treatment; coping with BPD; and financial burdens
Chiesa (2000) UK	Investigation of reasons for early discontinuation of specialised inpatient psychosocial treatment in a sample of people with personality disorder.	18 service-users Some had BPD-diagnosis others PD-diagnosis. Number not disclosed	Mixed methods semi-structured in-depth interviews. Symptom Checklist, Social Adjustment Scale	Being treated in institutional and punitive fashions, staff expecting too much of service-users; treatment organisation and delivery; dimensions of living in a therapeutic community.
Cunningham (2004) US	To understand from the client's perspective the experience of a DBT programme.	14 service-users Women diagnosed with BPD	Qualitative, ethnographic. Interviews	Experience of individual therapy; skills training; institutional culture, uniform application of the programme, rules and excessive confrontation from staff – expectations of staff for progress.
Dickens et al. (2016) UK	To explore the lived-experience of women prescribed clozapine for borderline personality disorder	20 service-users with BPD-diagnosis in secure care	Qualitative, semi-structured interviews; thematic analysis	Evaluate benefits as profound; subjective wellbeing improved; understanding of self, awareness, feedback from others on improvement; self-management, and/ facilitated engagement in psychotherapy
Dor (2015) New Zealand	To explore and describe the lived world of patients with BPD in order to develop supporting guidelines to improve non-compliance.	10 service-users with BPD diagnosis	Qualitative Interviews	The relationship with the clinician, the overwhelming feelings experienced by the patients and the sense of futility in treatment. These were all linked to the lack of hope the patient felt regarding their clinician, ever being able to manage their continuously oscillating emotions and the purpose of treatment.
Dunne & Rogers (2013) US	To explore carers' experiences of the caring role, and to explore carers experiences of mental health and community services.	13 families of people diagnosed with BPD	Qualitative Focus groups; thematic analysis	Carers needs, research diagnosis themselves; mixed feedback on CPA; support from mental health services; life changing nature of being a carer, financial strain.
Fallon (2003) UK	To analyse lived experiences of participants contact with services; describe their impact; and utilize the users' accounts to inform the perceived role and function service provision.	7 service-users with BPD-diagnosis	Qualitative. Grounded theory; unstructured interviews; thematic analysis	Themes: 1. The service response; 2. -living with BPD distressing.; 3. travelling through the system- a journey, 4. admissions; progress and relapse; 5. crisis intervention

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Author / country /date	Aim / research questions	Participants	Method / Data collection	Findings
Giffin (2008) Australia	To explore the treatment-related experience of families whose close relative has BPD and a history of self-harm	4 families of people diagnosed with BPD	Qualitative Unstructured interviews; thematic analysis	Mental health system and family. Admissions
Hegge (2011) USA	The subjective experience of women in treatment for BPD	15 service-users with BPD-diagnosis	Qualitative Interpretivist perspective; semi structured interviews; thematic analysis	Shame; self-stigma, staff attitudes dismissive 'feel dirty' suicide attempts related to shame; people don't know what BPD is; professionals don't want to deal with it
Helleman (2014) Netherlands	To describe experiences of brief admission for crisis in BPD	17 service-users with BPD-diagnosis	Qualitative Descriptive phenomenological thematic analysis	Organisation of brief admission; admission procedure; quality of contact with nurse; time out from daily life; rest; value for the patient.
Hodgetts et al. (2007) UK	The experience of DBT for BPD	5 service-users with BPD-diagnosis	Qualitative Semi structured interviews Interpretative phenomenological analysis	Joining a DBT Programme (external and internal factors); experience of DBT (specific and non-specific factors); and evaluation of DBT (change, evaluation and role of the past and future)
Horn et al. (2009) UK	To explore service-users experience and understandings of being given the diagnosis of BPD	5 service-users with BPD-diagnosis	Qualitative Semi structured interviews Interpretative phenomenological analysis	Knowledge as power; uncertainty about what diagnosis means; diagnosis as not fitting; hope and possibility of change.
Hummelen et al. (2007) Norway	To explore the reason for premature termination from outpatient group psychotherapy following intensive inpatient therapy	8 service-users with BPD-diagnosis	Qualitative Grounded theory, thematic analysis Interviews	Difficult transition moving in from another group; discharge from day treatment; group therapy too distressing; outpatient therapy group not sufficient; unable to make use of group; complicated relationship with the group; too much external strain; desire to escape; no interest in further therapy found other solutions
Katasakou et al. (2012) UK	To explore what people with BPD view as recovery;	48 service-users with BPD-diagnosis	Qualitative Semi structured interviews; thematic analysis	Personal goals and achievements during recovery; taking control of emotions; improving relationships; balancing personal goals with service targets; people saw recovery in stages; and had problems with the word 'recovery'.
Katsakou (2016) UK	Exploring participants' perspectives on recovery from BPD	48 service-users with BPD-diagnosis, 15 therapists and 6 relatives.	Qualitative Semi-structured interviews	Three central processes that constituted service-users' recovery journey: fighting ambivalence and committing to taking action; moving from shame to self-acceptance and compassion; and moving from distrust and defensiveness to opening up to others. Four therapeutic challenges needed to be successfully addressed: balancing self-exploration and finding solutions; balancing structure and flexibility; encouraging service-users to confront interpersonal difficulties and practise new ways of relating; and balancing support and independence.
Koekkoek et al. (2009) Netherlands	To establish effects of preventative psychiatric admission of patients with BPD on the rate of agreement over treatment and patient's views..	8 service-users with BPD-diagnosis	Mixed methods Semi structured interviews, thematic analysis	Core elements of intervention- time out from daily life, hassles, reduced responsibility, contact with fellow sufferers, conversations with professionals control over treatment, awareness of vulnerability, recognition of problems and needs.

## Users' experiences of BPD services

Author / country /date	Aim / research questions	Participants	Method/ Data collection	Findings
Lariverie et al. (2015) Canada	To capture experience of recovery in women with BPD who had participated in a therapy programme	12 service-users with BPD-diagnosis	Qualitative Semi structured interviews; thematic analysis	Referral to services a positive turning point; 'recovery' not best term to use; being given information helped; healthy relationships, broad social support network; appropriate and useful help form services, family and friends facilitated recovery; having knowledge about diagnosis and prognosis; obstacles were detrimental relationships; long delay in receiving the diagnosis
Lawn & McMahon (2015) Australia	To examine the experience of carers individuals with BPD, seeking help and their own needs	21 carers of people with BPD-diagnosis	Survey Online survey monkey	Significant exclusion experienced; Education for GPs; Improve skills and attitudes; Specialist carers support needed with distinctive information and education; Significant challenges and discrimination when attempting to engage with and seek support from services; Community carer support services perceived as inadequate
Lawn & McMahon (2015) Australia	To understand the experiences of seeking and receiving support from public and private health systems for Australians with a diagnosis of BPD.	153 service-users with BPD-diagnosis	Quantitative Online survey monkey	Being given an adequate explanation about diagnosis – 45% who did not receive adequate explanation had been diagnosed > 5 years previous. Psychotherapy rated most useful. 65% reported being treated disrespectfully, particularly when inpatients: Usefulness of other supports mixed. Psychiatrists and psychologists found to be most supportive in assisting understanding of feelings; GPs greatest capacity to respond in a crisis. Mental health workers the least responsive..
Lovell & Hardy (2014) UK	To explore the lived experience of BPD in a forensic setting.	8 service-users with BPD-diagnosis	Qualitative Semi structured interviews; interpretive phenomenological analysis	1. Identity – being in a secure setting contributed to partial identity loss;. 2. Diagnosis helped explain their behaviour; 3. Power – the service having power over their lives. Trying to gain power seen as important tension – suicidal thoughts could be a way of gaining power. 4. Protection and containment – being protected from themselves. Felt let down by other services who had failed to protect them. 5. Confusion – felt unable to explain or articulate their experiences
McSherry et al. (2012) Ireland	The study examined service-user's perspectives on the effectiveness of an adapted DBT programme, delivered within a community adult mental health setting.	8 service-users with BPD-diagnosis	Qualitative Semi structured interviews; thematic analysis	1. Evaluation of therapy; 2. Treatment impact: renewed sense of identity
May (2015) Australia	To explore BPD patients' experiences of receiving Schema Therapy (ST) and therapists' experiences in delivering ST.	8 service-users with BPD-diagnosis	Qualitative Semi structured interviews, thematic analysis	ST reportedly led to greater self-understanding, better self-awareness of emotional processes. The process of ST was perceived as <i>necessarily</i> emotionally confronting, ST experiential techniques and some therapeutic group factors perceived as beneficial e.g., - sense of connection among group members. On the other hand there exists a possible interplay between level of patient dysfunction within the group and therapists' ability to manage group conflict
Morris et al. (2014) UK	To explore the experiences of individuals with a diagnosis of BPD in accessing adult mental health services and better understand which aspects of contact with services can be helpful or unhelpful.	9 service-users with BPD-diagnosis	Qualitative Semi structured interviews; inductive thematic analysis	The diagnostic process influences how users feel about BPD; non-caring care – unreliable, disjointed, poor communication; reactive rather than proactive; felt defined by the label. Requesting psychological therapies. Emotional support. Accommodating staff highly valued but many staff had a limited understanding of needs, and difficulties.
Nehls (1999) US	To generate knowledge about the experience of living with BPD	30 service-users with BPD-diagnosis	Qualitative, semi-structured interviews; interpretive phenomenological analysis	Treatment and care experience included living with limited access to care
Nehls (2001) US	To explore case management services from the perspective of community mental health centre clients with BPD. By providing descriptions and interpretations of the day to day experience of having a case manager.	18 service-users with BPD-diagnosis	Qualitative Semi structured interviews; interpretive phenomenological analysis	Benefits: Treats me like a person; More than a case manager, Long-term relationship; Person centred, comprehensive, continuous, - relationship most potent t factor

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Author / country /date	Aim / research questions	Participants	Method/ Data collection	Findings
Perseus et al. (2003) Sweden	To investigate patients' and therapists' perception of receiving and giving DBT.	10 service-users with BPD-diagnosis	Qualitative Semi structured interviews; thematic analysis	1. Therapy effect. 2. Effective components. 3. Unhelpful aspects
Perseus (2006) Sweden	Investigate how women patients with BPD experience suffering, quality of life and encounters with psychiatric services Describe how patients and professionals experience giving and receiving DBT	10 service-users with BPD-diagnosis	Qualitative Semi structured interviews; thematic analysis	Personnel added to suffering but could also be helpful in alleviating and relieving suffering by being respectful, understanding and validating. Experiences of not being understood – disrespectful and condemning attitudes perceived as no-one cares or actual hostility. DBT viewed as lifesaving – made life bearable. Struggled to honour 1-year sign up to DBT.
Rogers & Acton (2012) UK	To explore the views, opinions and experiences of those diagnosed with BPD with regards to their experiences of medication as a treatment.	7 service-users with BPD-diagnosis	Qualitative Semi structured interviews; thematic analysis	Staff knowledge and attitudes. Lack of resources for BPD. Recovery pathway for BPD
Rogers & Dunne (2011) UK	Explore the inpatient experiences of service-users with a personality disorder.	10 service-users with BPD-diagnosis	Qualitative Semi structured interviews; thematic analysis	Five super-ordinate themes: practicalities of ward life; having a voice; revolving door patients; the power of sectioning and the 'PD' label. Concerns over staff attitudes and inpatient safety. Positive developments included listening to inpatient feedback and joint decision-making.
Rogers & Dunne (2013) UK	To explore experiences individuals diagnosed with BPD of the Care Programme Approach (CPA) while under the care of a community mental health team	7 service-users with BPD-diagnosis	Qualitative Semi structured interviews; thematic analysis	Understanding BPD and recovery highlighted as difficulties. The struggle of having a voice in CPA meetings and the lack of information they received in the CPA process. Deliberation between progression versus consistency and moving on from services. Challenges of accessing treatment and lack of follow up in the CPA process.
Veysey S (2014) New Zealand	Discriminatory and beneficial experiences shared by people with a BPD-diagnosis focussing on their interactions with health professionals participants found helpful from health professionals	8 service-users with BPD-diagnosis	Qualitative Semi structured interviews; thematic analysis	1. Discriminatory behaviour from health professionals; 2. Helpful behaviour from health professionals and 3. The role of the individual. This third grouping acknowledges the active role of the client in their journey and the potential of individual practitioners to make a noted difference, positively and negatively, in clients' lives.
Webb & McMurrin (2009) UK	To elicit the views of service-users in a specific service on their experience of services sought and received for BPD.	7 service-users with BPD-diagnosis	Qualitative Delphi study	Respect, professionalism. support, practicalities.
Wilkinson (2008) UK	Explore the experiences of service-users in forensic mental health settings, including how service-users make sense of these experiences and their link to identity.	6 service-users with BPD-diagnosis	Qualitative Semi structured interviews; thematic analysis	Feeling vulnerable, experiencing life as having been interrupted and valuing positive experiences with other people. Their understanding of these experiences fell into four categories: biological, psychosocial stress, behavioural and experience as being senseless. Increasing opportunities for meaningful activities and relationships, and working with service-users to help them to find ways of coping with their internal experiences, to feel empowered and take an active role in their recovery, and to build positive identities.
Wolfendale Smith (2016) UK	Service-Users' and Professionals' Views of the Borderline Personality Disorder Diagnosis	10 service-users with BPD-diagnosis and 10 staff	Qualitative Semi structured interviews; thematic analysis	1. Stigma, internalisation, and social construction; 2. Essentialism, acceptance and compassion; change externalisation and shared understanding 3. Gaining access to treatment, gives me a community, reduces stigma

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**Supplementary Table S1: Qualitative study quality assessment**

Study	Study co-produced	Explicit aims	Qualitative method appropriate	Design appropriate	Recruitment strategy appropriate	Setting of data collection described	Data collection methods	Questions schedule included	Ethics discussed	Consent discussed	Description of analysis	Relationship considered	Clear statement of findings	Clarity of themes	Research valuable	Total (15 max)
Barnicot et al. (2015)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Bilderbeck et al. (2014)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Borshman et al.(2014)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Bradbury (2016)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Buteau et al.(2008)	-	+	+	+	+	+	+	-	-	+	-	-	+	+	+	10
Cunningham (2004)	-	+	+	+	+	+	+	-	-	+	+	+	+	+	+	12
Dunne & Rogers (2013)	-	+	+	+	+	+	+	-	-	+	+	+	+	+	+	12
Dickens et al (2016)	-	+	+	+	+	+	+	+	-	+	+	+	+	+	+	13
Dor (2015)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Fallon (2003)	-	+	+	+	+	+	+	+	+	-	+	-	+	+	+	12
Giffin (2008)	-	+	+	+	+	+	+	+	-	-	-	-	+	+	+	10
Hegge (2011)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Helleman (2014)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Horn (2009)	-	+	+	+	+	+	+	+	-	+	+	-	+	+	+	13
Hummelen (2007)	-	+	+	+	+	+	+	+	-	+	+	-	+	+	+	13
Hodgetts, et al. (2007)	-	+	+	+	+	+	+	-	+	-	+	-	+	+	+	11
Katasakou (2012)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	15
Katasakou (2016)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Koekkoek et al. (2009)	-	+	+	+	+	+	+	-	-	+	+	+	+	+	+	12
Lariverie (2015)	-	+	+	+	+	+	+	-	+	+	+	-	+	+	+	12
Lovell & Hardy (2014)	-	+	+	+	+	+	-	+	-	+	+	+	+	+	+	13
May (2015)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Morris (2014)	-	+	+	+	+	+	+	+	+	-	+	-	+	+	+	12
McSherry et al.(2012)	-	+	+	+	+	+	+	-	-	-	+	-	+	+	+	10
Nehls (1999)	-	+	+	+	+	+	+	+	+	-	+	+	+	+	+	13
Nehls (2001)	-	+	+	+	+	+	+	-	+	+	+	+	+	+	+	13
Perseius et al. (2003)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Perseius (2006)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Rogers, Acton (2011)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Rogers & Dunne (2011)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Rogers & Dunne (2013)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Veysey (2014)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Webb, McMurrin (2008)	-	+	+	+	+	+	+	+	-	+	+	+	+	+	+	13
Wilkinson (2008)	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	14
Wolfendale (2016)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	15

**Supplementary Table S2: Quality appraisal of mixed methods study**

	Study co-produced	Mixed methods				Quantitative					Qualitative				Integration		Total
		Explicit aims	Mixed methods design appropriate	Mixed methods design justified	Design for mixing methods described	Role clear	Method described	Method appropriate	Representative sample	Clear inclusion criteria	Role clear	Method described	Method appropriate	Recruitment appropriate	Relationship with the data considered	Integration of data relevant	
Chiesa et al. (2000)	-	+	+	+	-	0	+	+	+	-	-	+	+	-	-	-	8
Lawn & McMahon (2011a)	+	+	+	+	+	+	+	+	-	+	+	+	+	+	+	+	16
Lawn & McMahon (2011b)	+	+	+	+	+	+	+	+	-	+	+	+	+	+	+	+	16